Development and implementation of an ICF-based e-intake tool in clinical otology and audiology practice

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2019

document version
Publisher's PDF, also known as Version of record

Chapter 4:

Investigating rehabilitation needs of visually impaired young adults according to the International Classification of Functioning, Disability and Health

Published as:
van Leeuwen LM, Rainey L, Kef S, van Rens GHMB, van Nispen RMA.
Investigating rehabilitation needs of visually impaired young adults according to the International Classification of Functioning, Disability and Health
Acta Ophthalmologica 2015;93:624-650.

ABSTRACT

Purpose: To gain qualitative insight into the rehabilitation needs of visually impaired young adults (18–25 years) and how these needs relate to the International Classification of Functioning, Disability and Health (ICF) and patient characteristics.

Methods: Rehabilitation needs and patient characteristics of young adults (N=392) who applied for multidisciplinary services in 2012 and 2013 were obtained from structured and semi-structured intake records. Linking rules were used to assess how the needs related to Environmental Factors, Body Functions, Body Structures, and Activity and Participation (A&P) ICF components. The relationship between the type of rehabilitation goal and patient characteristics was assessed using multivariate logistic regression analyses.

Results: Most rehabilitation needs (67.6%; N = 510) were found on the A&P component of the ICF. Most prevalent needs were related to 'major life areas' (e.g., finding internship or job), followed by the chapters: 'mobility' (e.g., self-reliance in travelling), 'communication' (e.g., using communication devices and techniques), 'general tasks and demands' (e.g., psychological aspects of vision loss) and 'domestic life' (e.g., household tasks). Patients in one of the multidisciplinary rehabilitation centres (odds ratio (OR) = 7.07; 95% confidence interval (CI) [2.97–16.83]) and patients with comorbidity (OR = 3.82; 95% CI [1.62–9.02]) were more likely to report rehabilitation needs related to chapter E3 'support and relationships'.

Conclusion: 'Major life areas' prevail in the content of rehabilitation needs, but tend to overshadow topics regarding peer interaction and social, community and civic life. A suitable survey method for young adults with visual impairments is required that contains rehabilitation domains and goals relevant to their lives and development.

INTRODUCTION

Having a visual impairment significantly affects an individual's daily functioning and quality of life[1-4]. Research on the transition to adulthood for young adults with disabilities indicates that the process can be highly challenging[5]. Having to deal with a disability is likely to interfere with changes in the important life transitions, possibly resulting in psychological distress[6] and disruption in the individual's pursuit of developmental tasks[7]. Consequently, the transition to adulthood may be less successful which, in turn, may compromise a young adult's physical, social and psychological potential, and opportunities for full participation in adult life[8]. In making the transition from childhood to adult life, young adults who are blind or visually impaired may need information and advice specific to their needs. Rehabilitation services can play a role in helping young people recognize where the difficulties are and what can be done to overcome or to minimize them.

The transition comprises a series of developmental tasks and pursuits of life goals, for example completing school, gaining employment, independent living and selecting a partner[9-13], and is characterized by a longing for independence and autonomy. However, most reports on young adults with a visual disability only focus on the transition to and from educational services and on career planning (e.g., [14, 15]). Although dropout rates and graduation rates are normal among youths with a visual impairment[14], there is a gap in employment rates compared with youths without visual disabilities[15]. The study by Rainey et al. (2014)[16] on the rehabilitation needs of children and adolescents with visual impairments indicates that the transition process into adulthood already starts in the age group of 12- to 18-year-olds (i.e., adolescents). Rehabilitation needs of children aged < 12 years mainly focused on the life domains (according to the International Classification of Functioning, Disability and Health; ICF) regarding 'learning and applying knowledge' and 'mobility'. The focus in adolescents was much more related to independence issues such as self-care, running household tasks and finding appropriate secondary education. Adolescents with visual impairments also show increased interests in social relationships, including relationships with friends and intimate and romantic relationships[10, 17]. However, several studies found that adolescents with visual impairments experienced difficulties in this regard, threatening psychosocial development and the quality and maintenance of such relationships[9-12, 18, 19].

Although some elements essential to transition have been proposed, a synthesis of this information in relation to rehabilitation needs in young adults with visual impairments is lacking. Insight into topics that are affected by the disability during the transition period can be helpful to better understand adaptation to the visual impairment and may provide indications as to which additional support is needed. The ICF is generally accepted as a reference framework in rehabilitation[20] and especially the Activity and Participation (A&P) component of the ICF provides a common language for professionals when identifying

rehabilitation needs. Applying the ICF framework facilitates the identification and understanding of rehabilitation needs, as well as formulation of responses to the disability and health-related needs[21, 22]. To our knowledge, no study has comprehensively described and appraised the content of rehabilitation needs in young adults with a visual impairment. Therefore, this study investigates whether the shift in rehabilitation needs by different age bands found in the study of Rainey et al. (2014)[16] continues in the rehabilitation needs of young adults and how these needs fit the structure of the ICF. Also, the relationship between rehabilitation needs and various patient characteristics was investigated.

METHOD

Study design and setting

This study was a patient record study involving two multidisciplinary rehabilitation centres (MRCs): Royal Dutch Visio and Bartiméus, both located in the Netherlands. Patient records were anonymized. The study was approved as an amendment to a study protocol aimed at the development of intake modules for visually impaired children (0–18 years) by the Medical Ethical Committee of the VU University Medical Center, Amsterdam, the Netherlands.

Participants

All patient records of young adults who applied for multidisciplinary services between 2012 and 2013 were eligible for inclusion. Inclusion requirements involved the following: (1) young adults aged 18–25 years, (2) the record containing a signed rehabilitation plan with at least one rehabilitation goal and (3) the young adult was eligible for care at Royal Dutch Visio or Bartiméus. Eligibility requirements for care at Royal Dutch Visio or Bartiméus include criteria according to the World Health Organisation (WHO), where low vision is defined as a visual acuity < 0.3 but $\geq$ 0.05 (Snellen notation) and/or a visual field of <20° around the central fixation point, or other severe visual field defects (i.e., hemianopia or cortical visual impairment). In addition, blindness is defined as < 0.05 and/or a visual field of <10° around the central fixation point[23]. Furthermore, an individual is considered eligible for care at a MRC if the visual impairment causes limitations in activities of daily living (ADL) that cannot be solved by regular healthcare services[24].

Measurement outcome

The main outcome measure was the type of rehabilitation needs. Within the Dutch MRCs, rehabilitation needs are set during an intake procedure and documented in signed rehabilitation plans. Upon examination of the rehabilitation plans, two different intake methods were identified: a semi-structured approach and a structured approach.

Rehabilitation needs obtained from the semi-structured approach

A (scheduled) semi-structured intake procedure usually starts with a concise telephone conversation between the patient and a professional intaker from the MRC, to clarify the

rehabilitation needs. Rehabilitation needs are formulated into goals and documented by the intake professional in a predefined format, which follows the ICF structure. In this study, rehabilitation needs were obtained from these formats, and linking rules[25] were used to assess how these needs related to the structure of the Environmental Factors, Body Functions, Body Structures and A&P components of the ICF. This procedure was performed by one researcher (LvL). Patients' rehabilitation needs were translated into categories of the ICF to make the data accessible for evaluation.

The linking rule procedure comprises two steps. First, meaningful concepts were identified within the written rehabilitation goal. Second, all meaningful concepts were linked to the most precise ICF component (1st level), chapter (2nd level) and (sub) category (3rd and 4th levels). To enhance comparisons of frequencies within the study population, each meaningful concept that was linked to the 2nd, 3rd or 4th level was also given the ICF code on the corresponding higher ICF levels (e.g., meaningful concepts linked to the 3rd-level d830 were also linked to the 2nd-level d8 and the 1st-level A&P). If the concept could not be linked to the ICF classification, it was assigned the code 'not definable'. If the concept was not recorded in the ICF classification, it was assigned the code 'not covered'. An example of the linking procedure is presented in Table 1. A second researcher (i.e., LR) was consulted in case of uncertainty regarding the allocation of rehabilitation needs to the different ICF categories. The second researcher independently linked the need to the ICF. Discrepancies were resolved by a discussion between the two researchers in which a final allocation was chosen jointly.

TABLE 1. Example of the linking process of rehabilitation needs to corresponding ICF codes

1. Rehabilitation goal				
"Wants to know about her opportunities for higher education and work. Wants another cane. Wants another Daisy Player. Requires some mental support for the loss of vision."				
2. Meaningful concepts	**3. ICF linking**			
	1st level	**2nd level**	**3rd level**	**4th level**
Higher education	A&P	D8: major life areas	d830: higher education	NC
Work	A&P	D8: major life areas	d840-d859: work and employment	NC
Cane	Environment	E1: products and technology	e120: Products and technology for personal indoor and outdoor mobility and transportation	e201:Assistive products and technology for personal indoor and outdoor mobility and transportation
Daisy Player	Environment	E1: products and technology	e125: Products and technology for communication	NC
Mental support	A&P	D2: general tasks and demands	d240: Handling stress and other psychological demands	NC

NC = not covered

Rehabilitation needs obtained by the structured approach

Rehabilitation needs from structured intake records were obtained with the Participation and Activity Inventory (PAI) (formerly known as the Dutch ICF Activity Inventory, which is the adapted Dutch version of Massof's Activity Inventory[26]). Based on legal and organizational divisions, in the Netherlands young adults are part of the department of rehabilitation for adults and, consequently, the adult PAI version was applied to them. The PAI is administered by telephone. However, the questionnaire is not always applied to young adults. It is unknown why professionals choose to administer or not to administer the PAI. The PAI is structured on the basis of the A&P component of the ICF. The A&P component assesses nine separate ICF chapters: 'learning and applying knowledge', 'general tasks and demands', 'communication', 'mobility', 'self-care', 'domestic life', 'interpersonal interactions and relationships', 'major life areas', and 'community, social and civic life'. It was developed for adults with a visual impairment and was adopted by the two largest Dutch rehabilitation organizations for the visually impaired[27-30]. An activity is defined as 'the execution of a task', and participation has been defined as 'involvement in life situations'[21]. The PAI consists of specific activities, referred to as 'tasks', which are generally difficult for individuals with a visual impairment[29]. The rehabilitation needs that were identified with the PAI were collected at the goal level (e.g., mobility outside) and at the task level (e.g., cycling). The central question addresses how difficult it is for the client to carry out a purpose or task (e.g., How difficult is it for you to move around in your home, without someone else's assistance?). Response categories are as follows: not difficult (0), slightly difficult (1), difficult (2), very difficult (3) and not possible (4). In the patient records, tasks with a score of $\geq$1 were regarded as a rehabilitation need.

Statistical analyses

Descriptive statistics [frequencies, means and standard deviations (SDs)] were assessed for the different codes of the ICF that were used for linking and for the number of rehabilitation needs. To examine the relationship between type of rehabilitation needs and the various patient characteristics, that is gender, number of ocular diagnoses, visual acuity of the best eye, comorbidity (cognitive, hearing and neurological impairment) and type of MRC (Royal Dutch Visio and Bartiméus), multivariate logistic regression analyses were performed. Due to differences in documentation of rehabilitation needs between the two intake methods, the relationships between patient characteristics and ICF categories/PAI domains were analysed separately. To enable meaningful statistical analyses, visual acuity scores were transformed into logMAR scores, comorbidity was dichotomized into no comorbidity and $\geq$ 1 comorbidity, and the categorical variable type of MRC Royal Dutch Visio (versus Bartiméus) was used as reference group. To determine which variable could be included in the multivariable model, univariate regression analyses were conducted first, after which a forward stepwise routine was followed. An independent variable was considered (potentially) explanatory in the multivariate models if the p-value was < 0.1. To investigate whether patient characteristics cause rehabilitation needs in specific ICF categories/ PAI domains, the number of

rehabilitation needs in a particular ICF chapter were dichotomized into ≥ 1 versus no (0) rehabilitation goal in this chapter. All statistical analyses were performed using Excel 2010 and the Statistical Package for Social Science (SPSS) (version 20.0; SPSS Inc., Chicago, IL, USA).

RESULTS

Patient characteristics

Data extraction was carried out in 2014. Figure 1 shows the selection of patient records, the distribution of these records among the two assessment sites (i.e., Royal Dutch Visio and Bartiméus), and which type of intake method was used at these MRCs. The excluded patient records often included only registration for visual function testing (80%). Patient characteristics of the young adults of the studied patient records are presented in Table 2. No significant differences were found between the patient characteristics of both groups. Information on diagnosis was available in 315 records (98.7%). The most common diagnosis reported was nystagmus (16.8%), followed by optic atrophy (7.6%), conerod dystrophy (6.7%) and retinitis pigmentosa (6.0%).

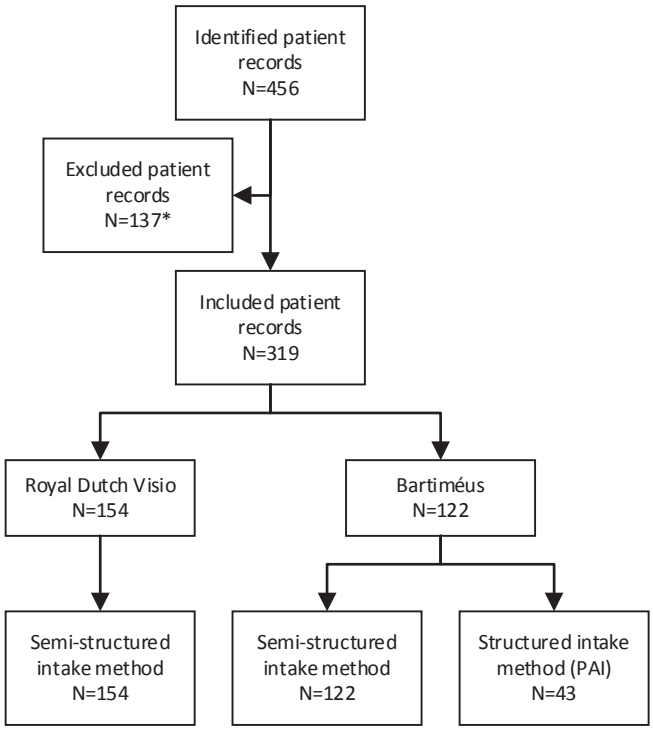

FIGURE 1. Flowchart of selection of patient records, the distribution of patient records among the MRCs, and type of intake method. **No signed rehabilitation plan available*

TABLE 2. Patient characteristics (N=319)

	Semi-structured intake (N=276)	*Structured intake (N=43)*
Age (years), mean ± SD (range)	21.3 ± 2.0 (18-25)	21.8 ± 2.3 (18-25)
Gender, % female	54.0%	65.1%
Visual acuity, logMAR (SD)[1]	0.66 (0.50)	0.65 (0.46)
Low vision, N (%)[2]	84 (30.4)	15 (34.9)
Blind, N (%)[2]	22 (8.0)	5 (11.6)
Comorbidity, N (%)[3]		
- ***Cognitive impairment***	36 (13.0)	2 (4.7)
- ***Hearing impairment***	4 (1.4)	2 (4.7)
- ***Neurological impairment***	18 (6.5)	2 (4.7)

SD = standard deviation; logMAR = logarithm of the minimal angle of resolution

[1]Semi-structured intake: N=172; 104 patient records did not include information on visual acuity; Structured intake: N=30 13 patient records did not include information on visual acuity.

[2] Semi-structured intake: 66 patients with information on visual acuity did not met criteria for low vision/blindness; Structured intake: 10 patients with information on visual acuity did not met criteria for low vision/blindness;

[3]N one of the patients was diagnosed with more than one co-morbidity simultaneously.

Rehabilitation needs based on semi-structured intake method

A total of 755 meaningful concepts were identified in 276 rehabilitation plan documents obtained from patient records which were based on the semi-structured intake method (mean 2.6, SD 2.1). Figure 2 presents the distribution of needs linked to the specific 3rd-level items in the chapters of 'Body functions' and 'Environmental factors'. Rehabilitation needs linked to 'Body functions' (7.7%, N = 58) were mainly about information on visual ability (i.e., B2 sensory functions and pain, specifically b210 'seeing functions'). A significant amount of rehabilitation needs were linked to 'Environmental factors' (21.2%, N = 160). Rehabilitation needs within this component most often concerned products for communication (55.0%), especially for everyday use or for education/employment. For example, young adults asked for assistance with reimbursement applications to health insurance companies, about purchasing a computer. The chapter E3 'support and relationships' was also frequently linked (28.1%), mainly concerning support for professionals (i.e., e355 'health professionals'). An example of such a rehabilitation goal was 'support, advice and guidance for the health professional to learn how to deal with the visual impairment of the young adult'.

Most rehabilitation needs (67.6%) could be linked to the A&P component of the ICF. The A&P chapter 'major life areas' (D8) was most frequently linked (24.5%), followed by the chapters 'mobility' (D4), 'communication' (D3) and 'general tasks and demands' (D2) (20.2%, 16.7% and 11.8%, respectively). The chapter 'domestic life' (D6) was also regularly linked to the rehabilitation needs (10.2%). Figure 3 shows the distribution of the specific 3rd-level items in the different chapters of the A&P component. Rehabilitation needs in the chapter 'major life areas' prioritized around higher education (d830) and options for work (d840–d859). Rehabilitation needs were formulated mainly as 'I need help to optimally structure my education' or 'I need help in finding a suitable intern-ship or job', as well as the broad

question ‘What are my (higher) education and job opportunities?’. In the ‘mobility’ chapter, concepts of independence and freedom in mobility prevailed. Rehabilitation needs were often linked to d460 ‘moving around in different locations’ and d470 ‘using transportation’; examples of rehabilitation needs included similarities of the phrases ‘learning new routes’ and ‘travel using public transportation’. Needs linked to the chapter ‘communication’ almost always related to improving computer skills, reflected by the high frequency of d360 ‘using communication devices and techniques’. Most of the rehabilitation needs linked to the chapter ‘general tasks and demands’ concerned needs related to category d240 ‘handling stress and other psychological demands’, referring to the request for psychological support in dealing with the (progressive course of the) impairment. With regard to the chapter ‘domestic life’, rehabilitation needs focussed on ‘living independently’ (i.e., d610 ‘acquiring a place to live’) and self-reliance in ‘carrying out household tasks’ (i.e., d630–d649 ‘doing housework’). Very few rehabilitation needs regarding ‘interpersonal interactions and relationships’ (D7) and ‘community, social and civic life’ (D9) were raised (3.5%).

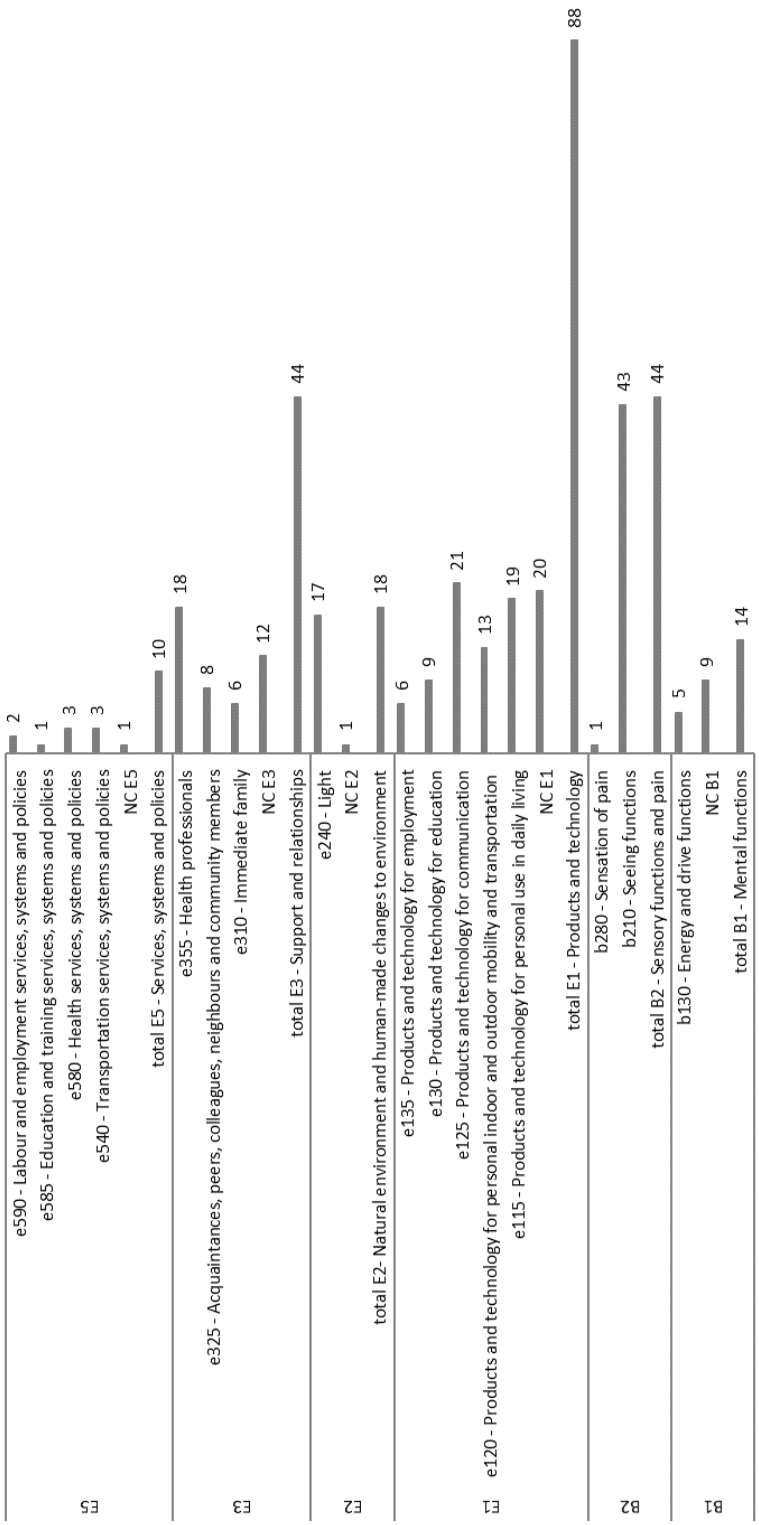

FIGURE 2. Frequency of ICF codes in the ICF component Body Functions and Environmental Factors, abstracted from the rehabilitation needs from the semi-structured intake method (N=286) of young adults with visual impairment. *NC = not covered*

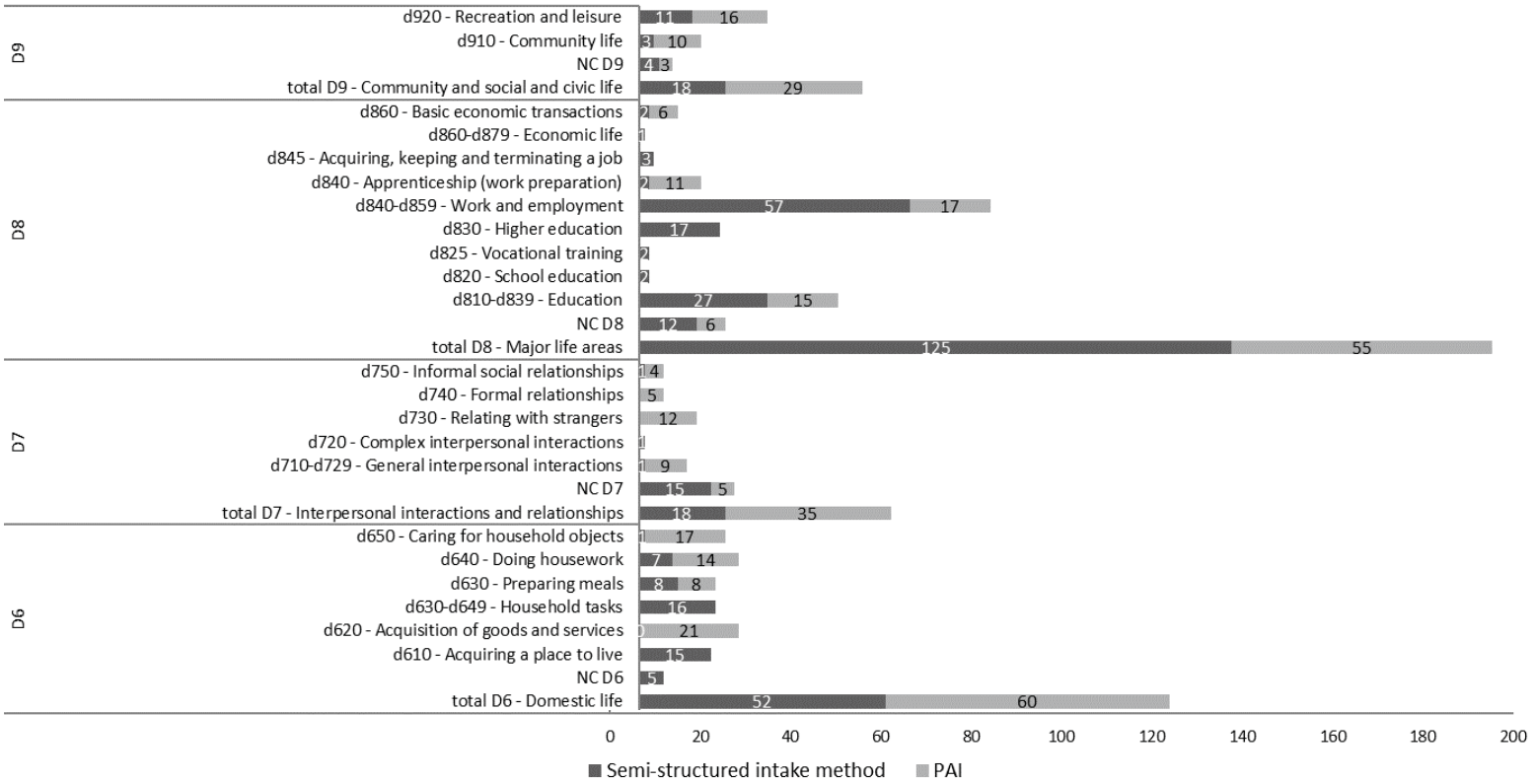

FIGURE 3. Frequency of ICF codes in the ICF component Activities and Participation, abstracted from the rehabilitation needs from the semi-structured intake method (N=286) and structured intake method (N=43) of young adults with visual impairment. *NC = not covered*

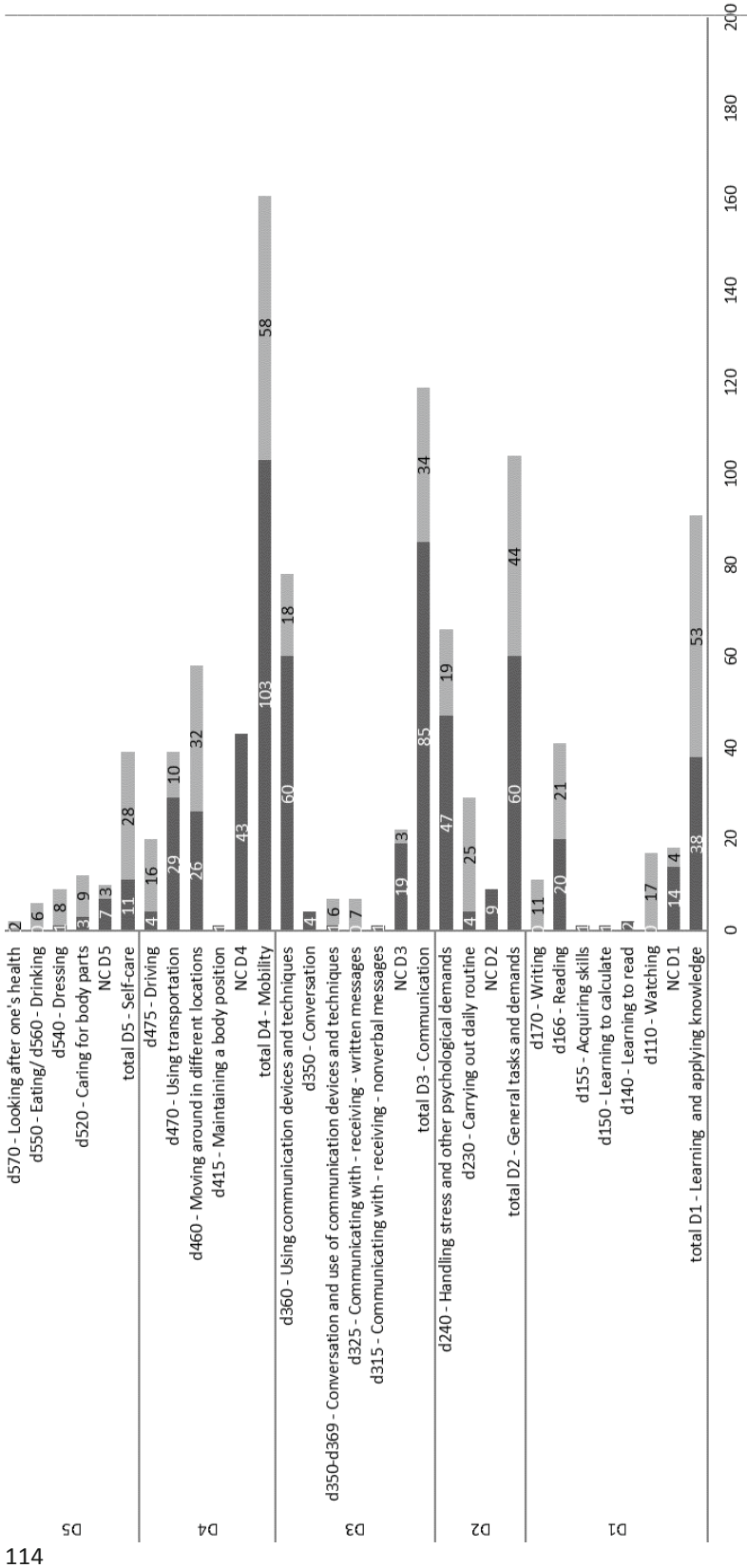

FIGURE 3. *Continued*

Rehabilitation needs based on structured intake (PAI)

In total, 43 patient records (13.5%) included scoring results on the PAI. The mean number of rehabilitation needs identified using the PAI was 10.6 ± 9.1. Topics that were reported in the PAI priority lists, that is the list of topics patients indicated they wish to receive rehabilitation, are also shown in Fig. 3. The scoring of the PAI shows a tendency similar to the results of the ICF linking mentioned above: topics regarding education and job application, mobility in different locations, computer skills, emotional aspects, and a variety of household tasks most frequently required priority. However, chapter D1 'learning and applying knowledge' received more emphasis, in which especially the task 'reading' was often mentioned.

Relationship between patient characteristics and ICF domains

Logistic regression analyses were conducted to assess associations between type of rehabilitation goal and an individual patient's characteristics. Univariate regression analyses showed that type of MRC was significantly associated with D1 'learning and applying knowledge' (OR = 0.15; 95% CI [0.05–0.45]), D2 'general tasks and demands' (OR = 3.82; 95% CI [1.62–9.02]) and D4 'mobility' (OR = 0.63; 95% CI [0.21–0.62]), indicating that for one MRC, it was more likely rehabilitation needs were extracted regarding general tasks and demands and less likely for learning and applying knowledge and mobility. Furthermore, patients with comorbidity (i.e. cognitive, hearing or neurological impairment) were more likely to report rehabilitation needs related to chapter B2 'sensory functions and pain' (OR = 2.48; 95% CI [1.22–5.05]) and less likely to chapter D8 'major life areas' (OR = 0.43; 95% CI [0.21– 0.88]). LogMAR visual acuity was related to having rehabilitation needs in E1 'products and technology' (OR = 3.92; 95% CI [1.89–8.15]) and not to having rehabilitation needs in D1 'learning and applying knowledge' (OR = 0.20; 95% CI [0.07–0.63]). With respect to chapter E3 'support and relationships', a multivariate regression model was found: patients of one type of MRC (OR = 7.07; 95% CI [2.97– 16.83]) and patients with comorbidity (OR = 3.82; 95% CI [1.62–9.02]) were more likely to report rehabilitation needs related to this chapter. No significant associations were found between patient characteristics and rehabilitation needs in ICF domains assessed with the PAI.

DISCUSSION

The present study provides insight into the content of rehabilitation needs as formulated in patient records of visually impaired young adults (aged 18–25 years) visiting Dutch MRCs. It was examined whether the shift in rehabilitation needs by different age bands found in the study of Rainey et al. (2013) continued in young adults. Furthermore, the relationship between type of rehabilitation needs and patient characteristics, and the intake method were evaluated. Linking rules and ICF classification allowed for a structured method to define the contents of rehabilitation goals.

Rehabilitation needs

Regarding the rehabilitation needs identified in this study, the focus seems to be on the A&P component of the ICF (i.e., linking frequency 67.6%), emphasizing that rehabilitation services of MRCs have their main focus on needs related to the execution of tasks and involvement in life situations. Items within the chapters 'domestic life' (i.e., living independently and household tasks) and 'major life areas' (i.e., education and work life) were among the highest percentages of topics identified in the rehabilitation needs, supporting the existing evidence that these are major themes in the transition to adult life[31, 32]. In particular, needs regarding education and work life prevailed in frequency. This is probably the most important life event in young adults' transition into adulthood, induced by expectations of society and their own ambitions. Attending postsecondary education and being competitively employed are considered normative social roles of young adulthood[33]. Having a job is the most direct means of achieving economic and residential independence[34]. Being a student in postsecondary education is regarded as an investment towards future employment and improving earned income[35, 36]. Achievement of these life goals has been linked to various positive outcomes among people with visual impairment (e.g., greater perceived self-efficacy and satisfaction with social contacts).

Another chapter of the A&P component that was frequently linked was 'mobility'. The identified rehabilitation needs in this chapter generally related to items regarding self-reliance, both in travelling (e.g., driving or using public transportation) and moving around in different places (e.g., finding the way to and in school/college). This finding is consistent with the increasing desire for independence and autonomy, which are fundamental concepts in the transition period. This tendency is also reflected in findings on the chapter 'domestic life', as the items that were linked were mainly focused on running a household independently. The frequent linking to the ICF chapter 'communication' (especially to codes related to using computer technologies) fits the picture of automation and constantly advancing technologies in this field. Nowadays, skills in this area are indispensable in the private, school and work environment. Although chapters and categories in the A&P component of the ICF are predominant in the rehabilitation needs, the component Environmental Factors should not be overlooked, as items under this component cover 21.2% of the identified rehabilitation

needs. The frequent linking to 'products and technology' and, more specifically, 'products for communication', correspond to the frequent linking in the 'communication' chapter of the A&P component. The finding that these items are often addressed as rehabilitation needs stresses the importance of including topics regarding the ICF component Environmental Factors in the intake procedure for young adults with a visual impairment.

The findings of the ICF linking in the A&P component complement the results of the patient record study in visually impaired children (0–18) by Rainey et al. (2014)[16]. Their results on the proportion of needs found per A&P chapter of the ICF included trends for age on the chapters 'mobility' and 'major life areas', meaning that, with increasing age, these domains were more often reported in the patient records. These are precisely the domains that were the most prevalent rehabilitation needs in the young adults' patient records. Furthermore, rehabilitation needs relating to the chapter 'domestic life' increased in frequency within adolescents; this rising rate appears to continue in the present study among young adults. In the present study, needs relating to the chapter 'interpersonal interactions and relationships' seem to require little consideration in young adults' lives. Although, overall, this domain is increasing in the study by Rainey et al. (2014)[16], the propensity weakened in adolescents. In addition, the chapter 'community, social and civic life' also received little attention in the formulation of rehabilitation needs by both adolescents and young adults. The low representation of these chapters in the rehabilitation needs of the present study is noteworthy, as they are inconsistent with the literature reporting that adolescents and young adults with visual impairments encounter challenges when it comes to social participation and inclusion in their communities of peers, relationships and leisure activities[10]. Social relationships play an important role in coping with visual impairment and – in adolescence and young adulthood, peer support in particular – which is reflected by the need for independence and the desire to want to fit in[10]. Moreover, social support might be especially important in the period of transition to adult life because of the many changes that take place. Although it is possible our studied population did not experience needs in this area, based on the literature[10, 12, 17-19], this seems unlikely. A possible explanation for the low percentage of rehabilitation needs in these chapters is that young adults may not feel comfortable sharing issues about relationships in their encounter with the intaker. Alternatively, the topic may have been overlooked by the professionals; a study by Boerner and Cimarolli (2005)[37] found that functional needs compared to relationship needs were more commonly addressed by vision rehabilitation services.

Rehabilitation needs and patient characteristics

Only a few significant associations were found between patient characteristics (gender, comorbidity, number of ocular diagnoses and logMAR visual acuity) and the type of rehabilitation needs (ICF chapters). Obviously, there were more needs reported with regard to visual ability for patients with more severely impaired vision, implying a greater need for optical aids or other assistive devices and questions on how they can improve reading ability.

Rehabilitation needs set for patients with a comorbidity almost always came from the supervisors (e.g., counsellors in a residential centre) of the young adult, explaining the finding that comorbidity creates questions regarding the visual ability of the young adult (e.g., 'What does the client actually see?') and the need for support for the supervisor (e.g., 'supervisor wants tips on how to properly handle the visual impairment of the client'). Most patients with comorbidity had a cognitive impairment. The fact that having comorbidity resulted in fewer questions on 'major life areas' is therefore not surprising, as the items under this chapter do not properly fit the life situations of most persons with cognitive impairments (e.g., daytime activity programme versus studying and working). These findings suggest that patients with coexisting impairments have (to some extent) different rehabilitation needs. Also, associations between the type of MRC and different types of rehabilitation needs (i.e., 'sensory functions and pain' and 'major life areas') indicate that either the MRCs serve different subgroups of young adults, which is unlikely, or that they differ in their intake methods. Differences might be overcome with a sector-wide structured approach to goal setting.

Rehabilitation needs and method of intake

The intake process within the MRCs evaluated in the present study did not appear to be consistent. The evaluated rehabilitation needs were obtained from either a semi-structured intake method or a structured intake method via the PAI. With regard to the rehabilitation needs set with the PAI, the same categories compared with the needs set by the semi-structured method were considered most frequently: mobility, household, and study and work. However, the systematic intake with the PAI resulted in more rehabilitation needs (mean number 11 versus 3) and also a better representation of needs on important domains found in the literature, that is domains regarding relationships and recreation and leisure are better represented as compared with the representation of these domains in the semi-structured intake approach. Significantly, more rehabilitation needs were identified in the chapter interpersonal interaction and relationships, and different social occasions in the leisure domain were scored a number of times as well. Apparently, inventorying these domains indicates rehabilitation needs on maintaining contacts and social activities, of which very few were identified using the semi-structured method. During the semi-structured intake, it seems more likely that the rehabilitation needs in areas that are more straightforward (i.e., economic and residential independence) overshadow rehabilitation needs in other domains (i.e., (romantic) relationships).

Unlike a former study in which semi-structured and structured methods (PAI) were compared[27], a direct comparison between these intake methods could not be performed in this study. Therefore, it cannot be concluded that the observed differences between the two methods are true. Bruijning et al. (2012)[27] found that only 22% of the rehabilitation needs identified by the PAI were present in the 'usual' semi-structured intake records. The systematic character of the PAI seemed to prevent important topics being overlooked.

Therefore, systematically identifying rehabilitation needs seems the preferred method. However, the current PAI approach is probably not optimal for young adults because the content of the items in the domains of the questionnaire was designed in a broader more general scope of 'adults', that is individuals already in adulthood versus individuals transitioning into adulthood. Moreover, no young adults were involved in the development of the PAI (i.e., mean age: 65, SD 16.5, range [38–90] years)[28]. Thus, the content of the PAI may not be fully consistent with the needs of young adults who experience many life situations for the first time in their lives. Furthermore, the PAI was only based on the A&P component of the ICF, whereas the rehabilitation needs identified in the semi-structured method suggest that other components of the ICF are also relevant (e.g., Environmental Factors).

Limitations

Several limitations need to be acknowledged. Because the rehabilitation needs studied were drawn from young adults who have pursued rehabilitation services (i.e., at Royal Dutch Visio or Bartiméus), this limits the generalizability of the results to these young adults with visual impairments as compared to those who do not seek such services. Furthermore, analyses in the present study relied on information entered in the patient record; this led to missing values on patient characteristics and, possibly, to missing rehabilitation needs that were addressed in the intake but were not documented in the record. The PAI was only administered to 43 young adults of whom no semi-structured goal-setting plan was available. These factors limited thorough comparison of semi-structured intake versus structured intake via the PAI. Moreover, no data were available on the reasons why the PAI was not administered in the other cases and, therefore, no valid explanation can be given for this event. It might indicate that the intaker judged that there was inadequate connection between the PAI and the target group. To be eligible for rehabilitation services at one of the MRCs, an individual has to meet the criteria for blindness or low vision of the WHO. Remarkably, information on visual acuity was poorly documented (missing rate 36.7%) and, of the patients for whom visual acuity was reported, 37.6% did not meet the WHO criteria. This finding may be explained by the fact that, although not reported, the criteria for visual field loss were met, or perhaps because (besides the WHO criteria) the Dutch guidelines for referral to MRCs state that services should also be provided to individuals who experience vision-related difficulties in activities of daily living that cannot be solved by regular healthcare services[24].

CONCLUSION AND PRACTICAL IMPLICATION

In conclusion, the focus of rehabilitation needs of young adults (18–25 years) assessed by intake professionals seems to lie in specific topics of the ICF, specifically in the categories education and work. This major focus tends to overshadow topics regarding peer interaction and community, social and civic life. Based on the results of the present study, the quality of rehabilitation for young adults with visual impairment in the Netherlands can be improved. Young adults with disabilities, including young adults with visual impairment, are susceptible for having unsuccessful transitions. Therefore, it is essential that rehabilitation services consider young adults in transition to adulthood as a separate group that needs specialized care. Moreover, an integrated and structured approach facilitates 'patient-centred care', which is considered an important marker in health care. Therefore, although comprehensive administration of important life areas is supported using a structured approach, the PAI approach for adults is not optimal for use among young adults. The results of the present study can be used to modify or adapt the current intake and treatment of young adults with visual impairments.

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